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TITLE: The impact of social support on hospital utilization patterns of older adults with

AUTHOR'S NAME: Julia Loosen

MAJOR: Biology, Sociology

DEPARTMENT: School of Medicine and Public Health, Department of Medicine

MENTOR: Melissa Dattalo, MD, MPH

DEPARTMENT(2): School of Medicine and Public Health, Department of Medicine

MENTOR(2): 

DEPARTMENT(2): 

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ABSTRACT

The impact of social support on hospital utilization patterns of older adults with multiple chronic conditions: a qualitative study

Five percent of the US population accounts for half of all health care costs. Members of this high-need, high-cost population are likely to be older, have multiple chronic conditions (MCC), and face complex social conditions. Social support is linked with health outcomes in models which have not been widely studied in this population. The objective of this study was to examine how social support is related to health care utilization based on the perceptions of high-need, high-cost older adults. 17 in-depth, open-ended interviews were conducted, and directed content analysis was used to analyze the interviews. Participants in all hospitalization subgroups discussed all types, sources, and settings of social support. The adequacy of social support was important to participants and had consequences for their health care. Further research is needed to fully understand the mechanism of social support and health and better represent the diversity of individuals who are high-need, high-cost.

Julia Loosen, Biology, Sociology
Author Name/Major

Melissa Dattalo, Department of Medicine
Mentor Name/Department

Julia Loosen
Author Signature
4/28/2018
Date

Melissa Dattalo, MD
Mentor Signature
The impact of social support on hospital utilization patterns of older adults with multiple chronic conditions: A qualitative study

Loosen, J.¹, Wyman, M. F.¹, Block, L.¹, Chapman, E.¹, Kennelly, K.², Gilmore-Bykovskyi, A.¹, Rogus-Pulia, N.¹,², Dattalo, M.¹,²

¹University of Wisconsin-Madison, ²The University of Iowa, ³William S. Middleton VA Hospital

Introduction

At a time when health care spending and policy is at the forefront of political debate, millions of Americans face the reality of living with chronic health conditions. Three out of four adults over 65 years old have multiple chronic health conditions (MCC), accounting for 66% of health care spending in the US, largely due to greater hospital use (HHS Office, 2014). The existing health care system in the US is not well equipped to care for individuals with complex MCCs as it was designed to manage acute illness. This problem will grow as the number of individuals with chronic health conditions is rising and is expected to reach 171 million people by 2030.¹

Individuals in the top 5% of health care spending nationally are sometimes described as belonging to a “high-need, high-cost” population which may not be well served by our current health care institutions. The medical conditions that high-need, high-cost individuals face are compounded by their complex social situations, such as unemployment and housing instability (Hasselman, 2013). It is estimated that 17% of adults over the age of 65 are isolated due to living alone and language barriers, disability, or geographic isolation; about half of these older adults are also considered economically insecure (Ortiz, 2011). As baby boomers age into older adulthood, the number of isolated individuals will likely grow as younger demographics are smaller than the boomer generation and fewer people will be available to provide support while demand grows. While social support is only one social determinant of health, it is a modifiable factor that can be addressed with interventions for high-need, high-cost individuals both at the individual and social network level. Therefore, it is important to consider how social support impacts health care utilization. The specific objectives of this study were to 1) examine how older adults with multiple chronic conditions and frequent hospitalizations perceive their
experiences of social support as it relates to their health and 2) explore the variation in social support experiences by patterns of hospital utilization.

**Literature Review**

**Social Determinants of Health**

The social determinants of health are a set of factors that contribute to overall health and wellbeing and include economic stability, physical environment, education, food, social environment, and the health care system (Heiman and Artiga, 2015). At a population level, it is estimated that about 15% of early deaths in the United States can be attributed to social circumstances while shortfalls in medical care account for only 10% of premature deaths (McGinnis, 2002). Despite this difference, the US continues to spend disproportionately less money on social services and more on health care than comparable Western nations (Heiman and Artiga, 2002). The social context of health is complex and can include social integration, social support systems, community engagement, and discrimination, so understanding how these determinants operate to produce outcomes of poor health among vulnerable populations is key to developing effective interventions to address health disparities.

For high-need, high-cost older adults these social determinants can play a large role in health and health care utilization. As previously discussed, a small number of patients accounts for a large portion of total health spending in the US. In a study of Medicare beneficiaries, individuals with ten or more chronic conditions were over 6 times more likely to be readmitted to the hospital than those with 1-4 chronic conditions (Joynt, 2013). Additionally, a study of potentially preventable hospitalizations among high-cost Medicare patients found that only 9.6% of hospitalizations were preventable (Joynt, 2013). However, the determination of preventable hospitalizations was based off of health conditions well-managed in outpatient settings (e.g. asthma, heart failure, diabetes) and did not consider other social determinants. In order to better understand this high-need, high-cost population, the social
determinants of health must be used to evaluate the causes of these patterns. A study of high emergency department-utilizing adults (n=19, mean age 51.6) identified the themes of childhood trauma and instability, past difficulty interactions with health care providers, and the importance of caring relationships with providers with respect to their health (Mautner, 2013). Among older adults with early hospital readmissions, the likelihood of being readmitted was increased when the individual lived alone, had limited education, lacked self-management skills, had fair or poor satisfaction with their primary care provider, lived in a socioeconomically disadvantaged neighborhood, or had an unmet functional need, indicating that socioeconomic factors are associated with hospital readmission (Arbaje, 2008; Ito, 2014; Kind, 2014). For severely ill individuals, self-reported reasons for early readmission include lack of clear and consistent communication with primary care providers (Long, 2013), lack of a caregiver and motivation for self-care, access to care and poor quality of care, and acceptance of condition and desire for aggressive care (Enguidanos, 2015). Complex social factors as well as medical factors are associated with excess health care utilization, including early hospital readmission, particularly among high-need, high-cost older adults.

Theoretical Perspectives: Social Support and Health

The role of social support in human health has long been a subject of interest and study. Theoretical perspectives can be classified into three general categories: stress and coping, social constructionist, and relationship perspectives (Lakey and Cohen, 2000). The stress and coping perspective focuses on the role of social support and the management of stress. It has been proposed that psychosocial factors play a role in disease as either stressor factors that increase susceptibility to illness or as protective factors that protect a person from illness and stress (Kaplan, 1977). When social support is absent, individuals have unmet needs which can lead to adverse physiological and psychological outcomes. Similarly, stress can change the stability, availability, and maintenance of social support (Cohen, 1992). Additionally, person-environment fit theory proposes that when a person
perceives that their environment is insufficient to provide for their needs, stress arises and can lead to psychological, behavioral, and physical strain. Over time these strains can lead to chronic health conditions (Edwards, 1998). Social constructionist perspective understands social support as a way to promote self-esteem and self-regulatory behaviors that are good for health. Hawkley and Cacioppo’s theory proposes that perceived social isolation leads individuals to become hypervigilant for social threats in the environment and these individuals have more negative expectations for social interactions which can contribute to adverse health outcomes via poor self-regulation (Hawkley, 2010). Finally, the relationship perspective is a grouping of theories that focus on the processes and qualities of relationships between individuals, including aspects of companionship, intimacy, attachment and low conflict (Lakey and Cohen, 2000). These relationship qualities are related to health by improving stress coping and increasing self-esteem, and it is hypothesized that relationships with these and other qualities may fill a fundamental, biological need.

Conceptualizing Social Support and Isolation

Social support is an important piece of an individual’s overall social context as it can be a target of interventions and has consequences for health. Conceptualizing social support and social isolation is critical to assessing an individual’s social situation using measures and scales. Social support can be defined as “psychological and material resources that help people adapt to change and cope with stress” (Elder and Retrum, 2012). This is distinct from social networks where an individual is part of a larger web of relationships (Elder and Retrum, 2012); however, both social support and social networks occur on the network level. The AARP Framework for Isolation in Adults Over 50 report constructs a definition of social isolation incorporating definitions from several literature sources:

Isolation is the experience of diminished social connectedness stemming from a process whereby the impact of risk factors outweighs the impact of any existing protective factors. A person’s lack of social connectedness is measured by the quality, type, frequency, and emotional satisfaction
of social ties. Social Isolation can impact health and quality of life, measured by an individual's physical, social, and psychological health; ability and motivation to access adequate support for themselves; and the quality of the environment and community in which they live.

It is important to consider both the objective measure of an individual's social isolation in addition to the subjective or perceived experience of social isolation. Loneliness is a similar concept to social isolation and is defined as feeling alone (Elder and Retrum, 2012); subjective social isolation and loneliness can be equated. Therefore, feelings of loneliness occur at the individual level while social support and social isolation occur at the network level, making them appropriate for targeted intervention.

Models of Social Support

A review of the literature provides several models that attempt to define the relationship between health and social support. A model developed by Heaney and Israel elucidates the relationship between social support and health (Figure 1). In this model, social networks and support relate to individual coping resources, stressors, organization and community resources, and health behaviors which in turn influence physical, mental, and social health (Heaney and Israel, 2002). The authors also indicate that social support is intended to be helpful by the giver but is not always perceived in a positive way by the receiver of support. It is also done without intent to influence behavior which distinguishes social support from social influence. Their conceptualization of the types of social support is based on previous research on social support and health and includes definitions developed by Cutrona and Suhr (1992) which are provided in Table 1. Cutrona and Suhr compiled types of social support discussed in previous research into five categories in their study on spousal support and stress. Mean participant age was 28.12 years (n=30). The five categories include informational, tangible, esteem, emotional, and network support. These types of social support are recurrent in literature on health and social networks and will be used as part of the coding scheme for this project.
Instrumental and emotional support have been studied in a variety of populations and are often used together in measures of social support and health outcomes, although the methods by which these supports are measured is inconsistent. Instrumental support for mothers is associated with reported child health (Turney, 2013) and a lack of social support is associated with depression among gay/bisexual men age 55+ (Ramirez-Valles, 2013). For hospitalized older adults, instrumental support was positively related to depressive symptoms while emotional support was negatively related (Gur-Yaish, 2013). Among black women in Detroit, instrumental support was associated with better general health and fewer depressive symptoms (Israel, 2002). In one case, instrumental support provided by adult children for depressed older adults (age 65+) was beneficial for those with severe limitations, but for those with moderate limitations too much or too little instrumental support increased depression (Djundeva, 2015). For patients with coronary artery bypass grafting (average age 65.7 years), those with high instrumental support had fewer cardiac conditions, better mental health, and better physical functions prior to surgery, and high levels of instrumental support predicted positive mental health outcomes after surgery (Barry, 2006). Among veterans with colorectal cancer (mean age 66.2 years), higher levels of emotional and instrumental support levels were correlated with better mental composite scale scores whereas lower physical composite scale scores were associated with higher instrumental support (Sultan, 2004). In a study of suicidal ideation, middle aged men (average age 48.6 years) were more likely to have suicidal ideation with low emotional support while middle aged women (average age 48.1 years) were more likely to report suicidal ideation with low instrumental support (Park, 2010). Emotional support was correlated with perceived health among gay men and relied on living with a partner (Ramirez-Valles, 2013), and emotional and instrumental support in childhood led to less biological dysregulation in adulthood (aged 34-84) (Slopen, 2016). Congestive heart failure patients with perceived low emotional support were more likely to have psychological distress (Yu, 2004). In a qualitative study of patients returning to the emergency room following a discharge from an internal
medicine unit (ages 64-91), participants attributed their ER visit to a lack of discharge instructions (informational support) and a lack of support at home (instrumental support) (Yat, 2015).

Informational, network, and esteem support have been less widely used in studies of social support. In breast cancer patients, informational support led to decreased anxiety about the disease and increased time spent with health care professionals, information seeking from health care professionals, and utilization of nurses for more information. In the same study, prostate cancer patients had decreased face-to-face consultations when they had more informational support and they relied on oncologists as the main source of informational support (Dubois, 2009). In another study of breast cancer patients (average age 66.7 years) older women and Latina women received less physician informational support than younger and white women, indicating that informational support from health care professionals may be dependent on patient characteristics including age (Maly, 2003). Post-partum Taiwanese women (average age 26.7 years) receiving informational support on post-partum depression had lower Edinburgh Postnatal Depression Scale (EPDS) scores than post-partum women in the control group who received no additional informational support (Heh, 2003). For osteoarthritis patients, low esteem support was correlated with increased disability defined by the Arthritis Impact Measurement Scales (AIMS), including physical, psychological, and pain components (Weinberger, 1990). In Native American and Native Hawaiian individuals (average age 52.7 years) with uncontrolled diabetes, a higher number of esteem and emotional support messages from a health care professional led to improved diabetes control (Robinson, 2017). Among older adults with chronic conditions (mean age 73 years), instrumental and network support was related to higher levels of satisfaction with participant’s ability to participate in everyday activities (Hand, 2013).

Not only are the components of social support associated with health outcomes, there is evidence that social support relates to health care utilization and therefore health care spending. For example, young adults with low socioeconomic status waited longer to utilize the health care system,
even with access to insurance, but young adults with high socioeconomic status were faster to utilize the health care system which was attributed to higher levels of informational and emotional support from family (Diaz, 2013).

Figure 1. Model proposed by Heaney and Israel (2002)

Heaney and Israel's model of social support and health hypothesizes that health is the result of a number of factors. Individual health behaviors, organizational and community resources, stressors, social networks and support, and individual coping resources all contribute to overall mental, physical, and social health.

Table 1. Types of social support and their definitions

<table>
<thead>
<tr>
<th>Type of social support</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informational support</td>
<td>Provision of advice, suggestions, and information that a person can use to address a problem; includes referrals to other sources of help, teaching, and reassessment of the situation (^1)</td>
</tr>
<tr>
<td>Tangible support</td>
<td>Provision of tangible aid and services that directly assist a person in need; includes loans, direct tasks, taking over another responsibility not directly related to an individual's stress, active participation, and willingness to help (^1)</td>
</tr>
<tr>
<td>Esteem support</td>
<td>Provision of information that is useful for self-evaluation; includes compliments, validation of individual's perspectives, relief of blame (^2)</td>
</tr>
<tr>
<td>Network support</td>
<td>Including others into support system, such as providing access to new companions, spending time with the individual, reminding individual of others who are available to be with (^1)</td>
</tr>
<tr>
<td>Emotional support</td>
<td>Provision of empathy, love, trust, and caring; includes physical affection, confidentiality, sympathy and empathy, listening attentively, encouragement, and prayer (^1)</td>
</tr>
</tbody>
</table>

\(^1\)Heaney and Israel 2002, \(^2\)Cutrona and Suhr 1992
More specific versions of health and social support models include a model proposed by David Frolich in his study of social support in people with chronic health conditions (Figure 2). Although not exclusive to older adults with MCC, components of his model can be applied to this population well. One component it includes that is not generally included in other models is distinguishing between social support that has been solicited or that has not been solicited. While this model has not been widely cited or validated through additional research, many of its components are congruent with more established models. For example, a need arises for a person with a chronic condition and needs to be met with informational, emotional, instrumental, and/or network support leading to health outcomes.

Figure 2. Model of chronic health conditions and social support

Frolich’s model of social support and health was developed using a population with chronic illness. In this model, an individual’s health situation is determined by their support environment which includes their needs and solicitation of social support. Their supports can influence their emotional and behavioral health.

In a conceptual model proposed by Dattalo et al. pertaining to high-need, high-cost individuals, formal caregivers such as health professionals or social workers may also be included in a patient’s social network. This is an extension of previous models which generally consider caregivers to be friends and family rather than professional or formal caregivers. Not only are these formal caregivers included in medical care and decision making as their primary function, but they also form long-term relationships
with high-need, high-cost patients and as such may be accepted into the patient’s social network (Dattalo et al. 2016).

**Measures of Social Support**

Based on theory, models, and prior research, several measures have been developed to quantify social support and isolation. The following measures are widely utilized in health care settings but provide inconsistent operationalization of social support concepts. These scales are also non-specific to older adults and/or patients with chronic conditions and may not accurately capture the complex social conditions these populations face.

Cornwell and Waite used data from the National Social Life, Health, and Aging Project (NSHAP) to develop indicators of social isolation. The authors conceptualize social isolation as having components of social disconnectedness and perceived isolation and thus developed respective scales for each (Table 2). Both scales were internally consistent (Cronbach's alpha > 0.70) and studied among a population of older adults (Cornwell and Waite, 2009). The authors found that social disconnectedness and perceived isolation are independently correlated with lower self-reported ratings of physical and mental health (Cornwell and Waite, 2009). The Cornwell and Waite scales include questions about social participation and group belonging which go beyond the social support structures described in the Heaney and Israel and Frolich models previously described. In one study of non-institutionalized older women with urinary and/or fecal incontinence, women with urinary incontinence reported feeling left out, felt they had a lack of companionship, and felt isolated more often than women without urinary incontinence. These women also reported having fewer than four friends more often that women without urinary incontinence. Women with fecal incontinence reported feeling often isolated and relied more on their spouse or partner than women without fecal continence (Yip, 2013). Social isolation as defined by the Cornwell and Waite scales was found to be associated with health outcomes among elders of Caucasian, Black, and Hispanic race/ethnicity (Miyawaki, 2015).
Table 2. Cornwell and Waite social disconnectedness and perceived isolation scales

<table>
<thead>
<tr>
<th>Social Disconnectedness Scale Questions</th>
<th>Perceived Isolation Scale Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social network size</td>
<td>How often do you feel lonely, that you lack companionship, left out, isolated from others?</td>
</tr>
<tr>
<td>Proportion of network that lives in household</td>
<td></td>
</tr>
<tr>
<td>Average frequency of interaction with network members</td>
<td>How often can you open up to members of family, rely on family, open up to friends, rely on friends, open up to spouse or partner, rely on spouse or partner?</td>
</tr>
<tr>
<td>Number of friends</td>
<td></td>
</tr>
<tr>
<td>Frequency of attending meetings of an organized group, socializing with relatives and friends, volunteering</td>
<td></td>
</tr>
</tbody>
</table>

The Lubben Social Network Scale (LSNS) (Table 3) is a widely used and highly validated scale used to evaluate social isolation in older adults. The LSNS was built upon the Berkman-Syme Social Network Index for use specifically among older adults. It includes components of frequency of social contact and reciprocity in relationships, with all components measuring subjective social isolation (Lubben, 1988). The abbreviated LSNS-6, as well as other variations of the measure, has also been studied among several populations and can be used to pinpoint individuals who may be at risk for social isolation and therefore be candidates for more extensive scales or interventions (Lubben, 2006). Low scores on the LSNS (indicating lack of social support) have been correlated with increased risk for extended hospital stays (Lubben, 1987; Lubben, Wellder, and Chi, 1989), all cause-hospitalization (Lubben, Wellder, and Chi, 1989; Mistry et al., 2001), delayed hospital discharge (Landerio, Leal, and Gray, 2016), and mortality (Rutledge et al., 2003). Low scores on the LSNS were also correlated with depression (Joo and Roh, 2016; Illiffe et al., 2007; Illiffe et al., 2009; Tang et al., 2005), suicidal ideation (Joo and Roh, 2016;), impaired memory (Illiffe et al. 2009;), diminished functional ability (Illiffe et al. 2009;), fear of falling (Illife et al. 2009), fewer good health practices (Lubben, 1988; Shimada, 2014), higher risk of malnutrition (Boulos et al., 2016; Arai and Sakakibara, 2015; Romero-Ortuno et al., 2011), higher risk of stroke (Nagayoshi et al., 2014), low morale (Loke et al., 2011), less resilience (Wells, 2009),
cognitive impairment and poor mental health (Crooks et al., 2008; Shimada, 2014), sleep disruption among dementia patients (Eshkoor et al., 2013), less self-efficacy in doctor-patient interactions (Raymond, 2011), and perceived difficulty with activities of daily living and instrumental activities of daily living (Iliffe et al., 2007). Additionally, higher levels of social support as indicated by higher scores on the LSNS are associated with having advanced directives (Ko, 2010) and greater resilience (Slosser, 2015). One study indicated that higher scores on the family components of the LSNS meant participants were less likely to salt their food, more likely to get diabetes screenings, and more likely to have mammograms. Higher scores on the non-family components of the LSNS were associated with likelihood of exercising and having ever tried to lose weight (Levy-Stoms, 2006).

Table 3. Lubben Social Network Scale (LSNS) Components

<table>
<thead>
<tr>
<th>Family Networks</th>
<th>Friends Networks</th>
<th>Interdependent Social Supports</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number seen monthly</td>
<td>Number feels “close to”</td>
<td>Has a confidant</td>
</tr>
<tr>
<td>Frequency of social contact</td>
<td>Number seen monthly</td>
<td>Is a confidant</td>
</tr>
<tr>
<td>Number feels “close to”</td>
<td>Frequency of social contact</td>
<td>Relies upon and helps others</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Living arrangements</td>
</tr>
</tbody>
</table>

The Duke Social Support Index (DSSI) (Figure 3) originated from interviews with middle-age and elderly adults diagnosed with depression which revealed that social network size and the subjective experience of social support were important for predicting depression symptoms at follow-ups (George, 1989). It was later abbreviated for use with chronically ill older adults and includes components of subjective social support, instrumental support, and social interaction and participation (Koenig, 1993). Low scores on the DSSI has been correlated with depression (Warison, 2017; Hou, 2015; Lyness, 2006; Evans, 2009; Poleshuck, 2006), hopelessness and anxiety (Zhang, 2012), difficulties with activities of daily living and instrumental activities of daily living (McLaughlin, 2012), self-neglect (Dyer, 2007), and
symptomatic coronary heart disease (Strodle, 2003). High levels of social support measured by the DSSI are associated with shorter durations of mania in patients with bipolar disorder (Beyer, 2014), and life satisfaction (Evans, 2009).

Figure 3. Original Duke Social Support Index

1. Number of parents and grandparents who live within 1 hour’s travel.
2. Number of brothers and sisters who live within 1 hour’s travel.
3. Number of children who live within 1 hour’s travel.
4. Amount of time spent talking with other people at work or school.
5. Households.

Social Network Subscale
4. Number of family members within 1 hour that subject can depend on or feel close to.
5. Number of times past week spent time with someone not living with.
6. Number of times past week talked with friends/relatives on telephone.
7. Number of times past week attended meetings of clubs, religious groups, or other groups that you belong to (other than at work).
8. Subjective Support Subscale
9. How often do you feel lonely?
10. Do family and friends understand you?
11. Do you feel useful to family and friends?
12. Do you know what’s happening with family and friends?
13. Do you feel listened to by family and friends?
14. Do you feel have a definite role in family and among friends?
15. Can you count on family and friends in times of trouble?
16. Can you talk about your deepest problems?
17. How satisfied are you with relationships with family and friends?
18. Do you need additional help?

Instrumental Support Subscale
19. Does family or friends ever help in any of the following ways:
20. Help you when you are sick?
21. Shop or run errands for you?
22. Give you gifts (presents)?
23. Help you out with money?
24. Fix things around your house?
25. Keep house for you or do household chores?
26. Give you advice on business or financial matters?
27. Provide companionship to you?
28. Listen to your problems?
29. Give you advice on dealing with life’s problems?
30. Provide transportation for you?
31. Prepare or provide meals for you?
32. Help take care of small children?

Other Items
33. Are you satisfied with how often you see your friends and relatives?
34. Is there at least one person with whom you have a close, lasting relationship?
35. Are you presently married or currently living with someone as though married?

Other commonly used scales are the UCLA Loneliness Scale and the MOS Social Support Survey, but these scales will not be used to inform this project as their components are very similar to or the same as the previously described measures and models; they include aspects of companionship, ability to rely on or turn to others for help, feelings of isolation, and the provision of emotional, information, and tangible support (Russell, 1978; Sherbourne, 1991). Overall, the measures and models described follow several themes. First, who is part of an individual’s social network (friends, family, and group belonging or participation). Second, what types of support are being provided to the individual with
needs. Finally, if the support is wanted, sought out, and sufficient to meet the individual's perceived needs.

Methods

Methodological Approach and Study Design

We used directed content analysis methodology in this study and applied it to interview text data. Qualitative research is used in cases where a research problem cannot be easily addressed using quantitative approaches. Directed content analysis is a qualitative method used to gain insight into text data, like interview transcripts, by analyzing themes and patterns. These patterns may provide evidence that supports or modifies existing theory (Hsieh and Shannon, 2005). Content analysis uses a preexisting theory or conceptual framework to develop codes, also known as categories, that are then systematically applied to the text data to describe previously incomplete components of that theory. The codes are derived from the literature and are usually common themes that frequently appear across theories. Codes are applied to text data; when an instance that matches an existing code is presented in the text data, it is labeled with the code. This process allows a large amount of text to be refined into several categories. As analysis continues, some data may not fit into the predetermined codes and can be used to develop new codes. After the categories have been determined, the relationships amongst them are identified.

This study was a secondary analysis of previously gathered in-depth interview data. Describing the connection between social support and hospital use will be generally defined using three components based on existing models: 1) the source of social support (informal, formal, or group); 2) the type of social support (informational, emotional, tangible, esteem, network) (refer to Table 1) and 3) how social support is given and received (frequency, setting, patient role in support). The participant’s appraisal of the social support was also recorded as adequate, inadequate, or unknown.
Social support from informal caregivers is a component of the Lubben Social Network Scale (LSNS) which focuses primarily on family and friends (Lubben, 1988). Formal caregivers may also be part of an individual's social network as described in the research preceding this project (Dattalo, 2016). Group belonging is described in the social disconnectedness and perceived isolation scales developed by Cornwell and Waite and is covered under the umbrella of social participation (attending group meetings, volunteering, going to religious services, and socializing with family and friends) (Cornwell and Waite, 2009). These scales also include components about informal caregivers much like the LSNS; both the LSNS and the social disconnectedness and perceived isolation scales focus on quantitative measures of support such as the frequency of support of the number of connections. The Duke Social Support Index (DSSI) includes questions regarding support from family and friends as well (Koenig, 1993). The types of social support and their definitions are likewise derived from the literature. Informational, tangible, emotional, network, and esteem support are presented by Cutrona and Suhr in their work on married couples and stressful events (Cutrona and Suhr, 1992). Heaney and Israel also include informational, emotional, tangible, and esteem support in their model; social networks provide these types of social support which in turn lead to certain health behaviors, physical and mental health outcomes, allow individuals to address stressors, and influence individual coping resources and use of community resources (Heaney and Israel, 2002). The DSSI has sections that focus on emotional support and tangible (labeled as instrumental support) (Koenig, 1993). The “how” category of the coding scheme is also derived from the literature and evolved over time as analysis progressed. The initial components of this category included frequency, setting, reciprocity and solicitation. Frequency of social support is measured in several scales including the LSNS, DSSI, and the scales developed by Cornwell and Waite (Lubben, 1988; Koenig, 1993; Cornwell and Waite, 2009). The setting of support (i.e. community-based resources, home, etc.) are included in the Heaney and Israel model and in the DSSI, which has questions about tangible support in the home as well as actions like running errands for an individual (Heaney and
Israel, 2002; Koenig, 1993). Reciprocity is an important component in the LSNS (Is the individual a
confidant for someone else?) as well as in the DSSI (Do you feel useful to family and friends?) (Lubben,
1988; Koenig, 1993). Finally, solicitation of social support is a component of the health and social
support model for individuals with chronic disease proposed by David Frolich (Frolich, 2014). The
adequacy of social support is a component of several of these models and measures and is particularly
salient in the previously discussed stress and coping models where unmet needs lead to adverse

Patient Population and Setting

The interview data were collected for a research study entitled “Understanding the experiences
of older adults with frequent hospital admissions: a grounded theory study” approved by the University
of Wisconsin-Madison Institutional Review Board. Participants (n=17) were an average of 72.5 years old
with an average of 9.4 chronic conditions and 5.7 hospitalizations in their highest utilizing year. 52.9% of
the participants lived alone. Recruitment sites were a complex case management organization, a home
health agency, a large academic hospital, and a dual-eligible patient managed care organization.
Caregivers of participants were also eligible to participate (n=4) and were an average of 64 years old.
Caregiver and participant interviews were conducted simultaneously; one case where a caregiver was
interviewed separately from the participant will not be analyzed for this study. Most interviews occurred
in the participant’s home unless otherwise requested.

Data Collection

This study was a secondary analysis of data collected in a previously described grounded theory
study that was intended to develop a conceptual model of factors influencing frequent hospitalization
patterns of older adults in a large academic health system (Dattalo, 2016). In-depth interviews were
conducted with participants (n=17) and any identified caregivers (n=3), using open-ended questions to
assess participant’s perceptions of their health and health care. Participants directed the interview and
follow-up questions were asked to provide additional clarifications. Follow-up phone interviews were conducted within 12 months of the initial interview. Sample interview prompts include:

Tell me a little bit about yourself.
How has your health affected your life?
What is it like to be in the hospital several times a year?
Tell me about your most recent hospitalization.
When you are not in the hospital, how do you care for your health?

No specific questions or probes about social support were provided to participants. Any description of social support was spontaneously offered by participants.

Data Analysis

We classified participants as 1) persistently high-need, high-cost; 2) no longer high-need, high-cost; or 3) high-need, high-cost but improving. Persistently high-need, high-cost participants had 3 or more hospitalizations in a 12-month period and continue to describe that pattern. No longer high-need, high-cost participants have had 3 or more hospitalizations in the past but are no longer being admitted that many times per year. High-need, high-cost but improving participants have 3 or more hospitalizations in a year but describe their number of hospitalizations decreasing over time. Their self-reported health status was also coded as worsening, improving, or stable. Each interview transcript was coded using the predetermined coding scheme derived from the literature (Table 4); a subset (5) of the transcripts was coded twice for Intercoder reliability checks. Data related to social support that did not fit into these predetermined categories were used to develop new categories not inferred from existing theories. The coding scheme was iteratively revised during the data analysis phase to ensure it operationalized the social support concepts accurately. The final coding scheme is presented in Table 5. To ensure validity, disagreements over coding were discussed at interdisciplinary group meetings until a consensus was reached.
Table 4. Initial coding scheme

<table>
<thead>
<tr>
<th>Domain of Social Support</th>
<th>Component of Domain</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who</td>
<td>Informal caregivers (family and friends)¹,¹</td>
<td>Increasing or decreasing hospital utilization</td>
</tr>
<tr>
<td></td>
<td>Formal caregivers (health care providers)²</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Group belonging (religious, civic, etc.)³</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Informational, ⁴, ⁵ Emotional, ⁴, ⁵ Network, ⁵</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Tangible aid, ⁴, ⁵, ⁶ Esteem ⁴, ⁵</td>
<td></td>
</tr>
<tr>
<td>How</td>
<td>Frequency, ⁴, ⁵, ⁶ Setting, ⁴, ⁵, ⁶ Reciprocity, ⁴, ⁶</td>
<td></td>
</tr>
<tr>
<td>Adequacy of needs</td>
<td>Adequate, inadequate, unwanted</td>
<td></td>
</tr>
</tbody>
</table>


Table 5. Final Coding Scheme

<table>
<thead>
<tr>
<th>Domain</th>
<th>Component</th>
<th>Detail</th>
<th>Adequacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who</td>
<td>Informal caregivers (family and friends)</td>
<td>Family, Friends</td>
<td>Adequate/inadequate/cannot tell</td>
</tr>
<tr>
<td></td>
<td>Formal caregivers (health care providers)</td>
<td>Clinic staff, Pharmacy staff, Hospital staff</td>
<td>Adequate/inadequate/cannot tell</td>
</tr>
<tr>
<td></td>
<td>Group belonging</td>
<td>Group type: religious, civic, work, etc.</td>
<td>Adequate/inadequate/cannot tell</td>
</tr>
<tr>
<td>What</td>
<td>Informational</td>
<td>Providing referrals/access to new service/staff, Caregivers &amp; person working across settings</td>
<td>Adequate/inadequate/cannot tell</td>
</tr>
<tr>
<td></td>
<td>Emotional</td>
<td>Direct Care, Medications, Financial, Other Responsibilities (housework, etc.)</td>
<td>Adequate/inadequate/cannot tell</td>
</tr>
<tr>
<td></td>
<td>Tangible</td>
<td>Wanted/unwanted support, reciprocity, active/passive in support relationship</td>
<td>Adequate/inadequate/cannot tell</td>
</tr>
<tr>
<td>How</td>
<td>Frequency</td>
<td>Adequate/inadequate/cannot tell</td>
<td>Adequate/inadequate/cannot tell</td>
</tr>
<tr>
<td></td>
<td>Setting</td>
<td>Adequate/inadequate/cannot tell</td>
<td>Adequate/inadequate/cannot tell</td>
</tr>
<tr>
<td></td>
<td>Patient Role in Support</td>
<td>Adequate/inadequate/cannot tell</td>
<td>Adequate/inadequate/cannot tell</td>
</tr>
</tbody>
</table>

Results

Participant Characteristics

The average age of participants who participated in the study was 72.5 years. The average number of chronic conditions was 9.4, and the average number of hospitalizations in the highest utilizing year was 5.7. The interview year was not necessarily the highest utilizing year; some participants that we interviewed were in a period of stability and not being hospitalized while others were still experiencing hospital admissions. 52.9% of participants lived alone. 10 participants where
categorized as persistently high-need, high-cost and 2 were categorized as high-need, high-cost but improving. 5 participants fell into the no longer high-need, high-cost category.

**Types of Social Support**

All 5 types of social support (tangible, informational, emotional, network, and esteem) were experienced by all participants regardless of their hospitalization pattern category (see Table 1). Responses in interviews about social support were spontaneous because no specific questions or probes about social support were provided. Themes emerged during data analysis about the common kinds of each type of social support. Tangible support provided to participants often was described as direct medical care, home chores, transportation, and grocery shopping. Typical examples of informational support included providing information about medications, medical conditions, and figuring out who to contact with questions (such as the primary care physician or a nurse). Emotional support was described as spending time with the participant and making them feel listened to. Esteem support included compliments about appearance and disposition. Finally, network support was often talked about as health care providers working together to address a specific medical problem for the participant, informal caregivers working with formal caregivers to decide treatment plans or pass along information, and case managers acting as coordinators of a participant’s care.
Table 7. Types of Social Support Discussed by Participants

<table>
<thead>
<tr>
<th>Type of Social Support</th>
<th>Participant Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tangible</td>
<td>&quot;...she would go once a month to the grocery store and she went to all different ones for me... [daughter] drives me, yesterday she drove me. My grandson upstairs does my laundry sometimes he now takes the garbage and stuff out to the dumpsters and does the laundry...if he's going to the store I'll have him pick up something and the [caregiver] that comes to clean she does most of my grocery shopping.&quot;—87-year-old woman in no longer high-need, high-cost subgroup</td>
</tr>
<tr>
<td>Informational</td>
<td>&quot;The classes at apartment complex you know how to eat right and deal with stress and other things that...they had one recently on how to fill out one of those medical forms where you...medical directives and stuff...&quot;—64-year-old man in no longer high-need, high-cost subgroup</td>
</tr>
<tr>
<td>Emotional</td>
<td>&quot;[Son] really gave me a lot of support with the diabetes...I was so scared to give myself a shot I just couldn't...But he was very good, he sat with me and the hospital sent someone from the diabetes center...we would practice with an orange and a syringe and my son did the same thing...he was very good about that.&quot;—67-year-old woman in high-need, high-cost but improving subgroup</td>
</tr>
<tr>
<td>Esteem</td>
<td>&quot;...one time the nurse practitioner said to me it was pleasant to work with me because I wasn't that grumpy old lady and I came in ready to talk and if we didn't always resolve the issue at least we worked on it.&quot;—87-year-old woman in high-need, high-cost subgroup</td>
</tr>
<tr>
<td>Network</td>
<td>&quot;Well I needed rides to church and [case manager] said that they would check on it and I should check with the people at my church and we talked three way to the people who are in charge of people helping get rides to the mass and so they were helpful there. Also, there about some drugs that I had been taking these and hadn't gotten them and hadn't gotten them I called a couple of times, so they called and got it straightened out for me, it's the little things like that that really helped.&quot;—81-year-old woman in high-need, high-cost subgroup</td>
</tr>
</tbody>
</table>

Sources of Social Support

The previously described types of social support were provided by three main sources of social support: informal caregivers, formal caregivers, and groups. Informal caregivers included spouses, children, siblings, friends, and neighbors. Formal caregivers included primary care physicians, specialists, nurses, case managers, and home health aides. Military and religious affiliations were examples of group belonging. While participants did not describe differences in the source of social support by hospital utilization category, they did express differences in the type of social support preferred from particular sources. Participants described preferences for informational support from formal caregivers. It was important for them to receive information from their primary care physician, nurses, pharmacists, and
case managers. Infrequently, informal caregivers provided informational support, and when this occurred it was perceived as unwanted:

"[Daughter] likes to be involved to be sure I'm taking my meds and I'm doing what I'm supposed to do...You know I don't mind her doing it although sometimes it maybe gets little overbearing...She rags on me pretty hard at times about eating, being a diabetic and all."—79-year-old man in high-need, high-cost subgroup

This man in the persistently high-need, high-cost category describes his daughter's involvement in his diabetes management as overbearing despite recognizing that her actions are intended to be helpful. Participants did desire emotional and tangible support from their informal caregivers as demonstrated in the following quote:

"And the doctor said it would take me at least a year...I want to be able to go out to lunch with my girlfriends and you know there's one that I go to see movies with and you know I'm not sure on my feet yet...I'm doing well, real well and I'm walking without the walker in therapy..."—68-year-old woman in high-need, high-cost but improving subgroup

This woman, who was recovering from a liver transplant, wanted to spend time with friends which falls under the category of emotional support. She describes her desire for companionship as a motivating factor for participating in physical therapy so she will be able to walk freely again.

Participant’s Role in Social Support

The participant’s role in engaging social support was not part of the original coding scheme and was not featured in the theory used to derive it. However, this category was added under the “how” domain after several participants discussed their role in support relationships and the consequences this has for their health care. Some participants described being passive in support relationships. This
included participants taking recommendations from their providers passively and not seeking information or asking questions:

"I mean whatever the docs say I do, I just put myself in their hands. And it seems to have been successful for all of us at this point. I don’t know how the docs feel but I’m comfortable just walking around in there and just acting like another patient."—60-year-old man in high-need, high-cost subgroup

Others described passively allowing informal caregivers to do tasks for them even though it was unwanted. This woman describes an aide who cleans her home:

"...I have to have somebody come in and help clean and that I, she cooks but it’s very hard at my age. When I had seven kids I would have loved if somebody came in and cleaned. But now no it doesn’t, I’m not that way anymore...I don’t really enjoy it."—87-year-old woman high-need, high-cost

Although she doesn’t like having someone clean her home, this participant discusses allowing it to continue because she knows it is the aide’s job to do so.

While some participants described being passive, others took an active role in relationships and in seeking information or resources. In relation to formal caregivers, several participants said that they wrote down questions or concerns and took them to doctor’s appointments to be addressed. Others said that they would advocate for themselves in appointments and ask for new options if a treatment plan would not work for them.

"...if you’re going to pay money to go see the guy least you can do is listen to what he has to say and if it makes halfway sense, do it. It don’t make no sense, tell him about it so he can come up with something that does make sense."—69 year-old-man in high-need, high-cost subgroup
This man states that he actively engages with his health care provider to come up with a treatment plan that makes sense for him. One woman describes her experience gaining her voice back after having a tracheostomy for a long period of time:

"...I told each and every one of them, I did a lot of kidding around with them and I don’t know how I did that with what I was going through, but that’s my personality so I just didn’t lose my personality. I told them beforehand, ‘You wait ‘til I can talk cause I’m going to have a lot of things to say to you.’ And when I did get my voice back...there was no more of them just walking out of the room.”—68-year-old woman in high-need, high-cost but improving subgroup

This participant would use strategies to advocate for herself even while unable to speak, including using a whiteboard to write notes to nursing home staff. With her ability to communicate restored, this patient is now able to articulate her needs and desires for her healthcare. Not every participant provided examples about being active or passive in support relationships, but enough data was present to add it to the coding scheme as a category.

Adequacy and Inadequacy of Social Support

Participants in all hospitalization categories described situations in which their social support was adequate and situations in which it was inadequate. Tangible support from both informal and formal caregivers was perceived to be adequate. Participants described having enough support from informal caregivers with home chores, transportation, meal provision, and financial help for example. Direct medical care as tangible support from formal caregivers was discussed as adequate as well. Additionally, emotional support from informal caregivers was adequate. Some participants described feeling supported by their families and friends and expressed satisfaction in spending time with them. Finally, networks support was generally described as adequate. This type of support included formal caregivers working together as well as informal caregivers working with health care providers to
coordinate care for participants. In the following example, a caregiver describes the importance of network support he provided to his wife in advocating for her to receive appropriate care at the emergency room:

"Got to the emergency room...The IV line, everything, only one time did he have to poke her so she wasn’t full of black and blue marks, she wasn’t full of tape and gauze all over the place. The medicine was in working, doing its thing, right there because he recognized me and because he remembered you know what we had discussed the last time she was in the hospital."—caregiver of 70-year-old woman in high-need, high-cost subgroup

In this case, a previously established relationship between a caregiver and an emergency room physician lead to an outcome the caregiver perceived to be better than past experiences in the emergency room with physicians who were unfamiliar with her situation. Case managers were also described as being important facilitators of network support. They were described as being helpful in juggling appointments, setting goals, relaying information, figuring out who to contact with medical questions, and providing a listening ear for participants.

In addition to perceiving certain aspects of social support as adequate, participants also discussed areas where social support was inadequate. Emotional support was sometimes perceived to be inadequate from formal caregivers when participants felt dismissed or not listened to. Participants valued having a personal relationship with their providers and appreciated when providers asked about their lives. One woman in the high-need, high-cost subgroup described her desire to be listened to regarding her medication regimen:

"I don’t want to live ‘til 100 and sit here in this house and not be able to do things, which is what it was amounting to... And since I've been off the cholesterol medicine, I have so much more energy...Give me some quality of life...it's just like you need to take a stick and beat it on
the table or something in order to get them to listen!"—87-year-old woman in high-need, high-cost

This participant expressed her need to be listened to in order for her quality of life to improve.

Informational support was also discussed as inadequate from formal caregivers. Participants felt that they sometimes did not have appropriate information about their medications and medical conditions and felt that they were not able to call their providers for fear of bothering them:

"...I think it's easier to communicate about that when they are calling you. I had a cardiac doctor call me one time to check on me on [me], again it was a cholesterol medication we were trying. And he called me to see how that medication was doing for me and I said ‘Oh doctor I hurt all over.’...it was like I could finally tell somebody but...had he not called me I probably would have waited the six months to see my doctor, you know what I'm saying?"—67 year-old-woman in high-need, high-cost but improving subgroup

This woman describes being hesitant to contact her doctor even when facing severe medication side effects. Only when her physician reached out to her directly was she able to notify someone of her condition which indicates the presence of a barrier between participants contacting their health care providers when seeking or relaying information. Even if participants did raise questions in interactions with physicians, some did not request more information if their initial questions were not addressed in an appointment or telephone encounter.

Discussion

Older adults with multiple chronic conditions and frequent hospitalizations described their experiences with social support types, sources, settings, and the levels of adequacy. Participants in all hospitalization categories discussed the types of social support. Formal and informal caregivers were discussed in each hospitalization subgroup, with formal caregivers being an important part of
participants' social networks. The patients discussed their own roles in engaging social support as being either active or passive which had consequences for the way they experienced their health care. The adequacy of social support was also important to participants and was discussed in all hospitalization subgroups. While participants described a variety of relationships between social support and their health and perceptions of their health care, the themes across hospitalization subgroups were more similar than different.

The existing models of social support and health that were used to develop the coding scheme for this project were consistent with the real-life experiences of older adults with multiple chronic conditions and frequent hospitalizations. This is despite the fact that these models were not developed using research on this specific population. The participants in this study discussed the importance of who is providing the support and the types of support which are included in the models used to develop the coding scheme. The results of this study allowed us to add components to existing knowledge about what is important to high-need, high-cost individuals in their health. While we often think of social support occurring at home and coming from informal caregivers, in this study formal caregivers were an important part of participant's social networks. Models of social support and health include components about family and friends of support, but formal caregivers are not often included. Additionally, participants described their own role in support relationships as active or passive allowing this also be added as a category. In existing models, this may be conceptualized as "health behaviors" or some other form of personal engagement, but it may be helpful to include the patient's role in support relationships in future models of support as health is a product of both external and internal factors. Finally, our coding scheme included the adequacy of support which allowed us to evaluate participant's descriptions of social support from their perspective. Social support models and measures often evaluate an individual's social network using quantitative questions (such as "How many times do you see a family
member per week?" or "How many friends live within 1 hour of your home?"") which may not provide a comprehensive picture of the quality of social support.

**Limitations**

There are important limitations to this study. Operationalizing theory into codes can be subject to individual bias, as can coding instances of social support in the transcripts. This was addressed by taking the initial coding scheme and applying to a subset of the transcripts by two study team members. The codes were then compared by these two team members for agreement; in cases of disagreement, the codes were discussed by the interdisciplinary team until consensus was reached. Additionally, the results of this study are limited in their generalizability. While the results reflect the lived experiences of our study participants, they were all white, lived in a single geographic region, and were affiliated with primarily one academic health system. In reality, the high-need, high-cost population is diverse and has diverse needs.

**Implications**

Potential interventions to better meet the needs of patients with multiple chronic conditions and frequent hospitalizations may target areas social support areas described as inadequate by participants in this study. In this case, creating pathways for communication where high-need, high-cost participants can access medical information in a way where they feel listened to may address the perception of inadequate emotional support from health care providers. High-impact and scalable interventions targeting social networks of this population may be effective in providing more avenues to advocate for unmet needs, as utilizing network support was commonly effective in acquiring other types of support, including informational support or tangible support. Participants described case managers and care coordinators as important in their network support, so interventions utilizing these formal caregivers may also prove effective. However, further study is needed, both qualitative and
quantitative, to fully understand the mechanisms by which social support is related to hospitalizations and health outcomes on an individual and population-wide scale. Because high-need, high-cost patients are a diverse group, multi-site research is needed to more fully represent this population.

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